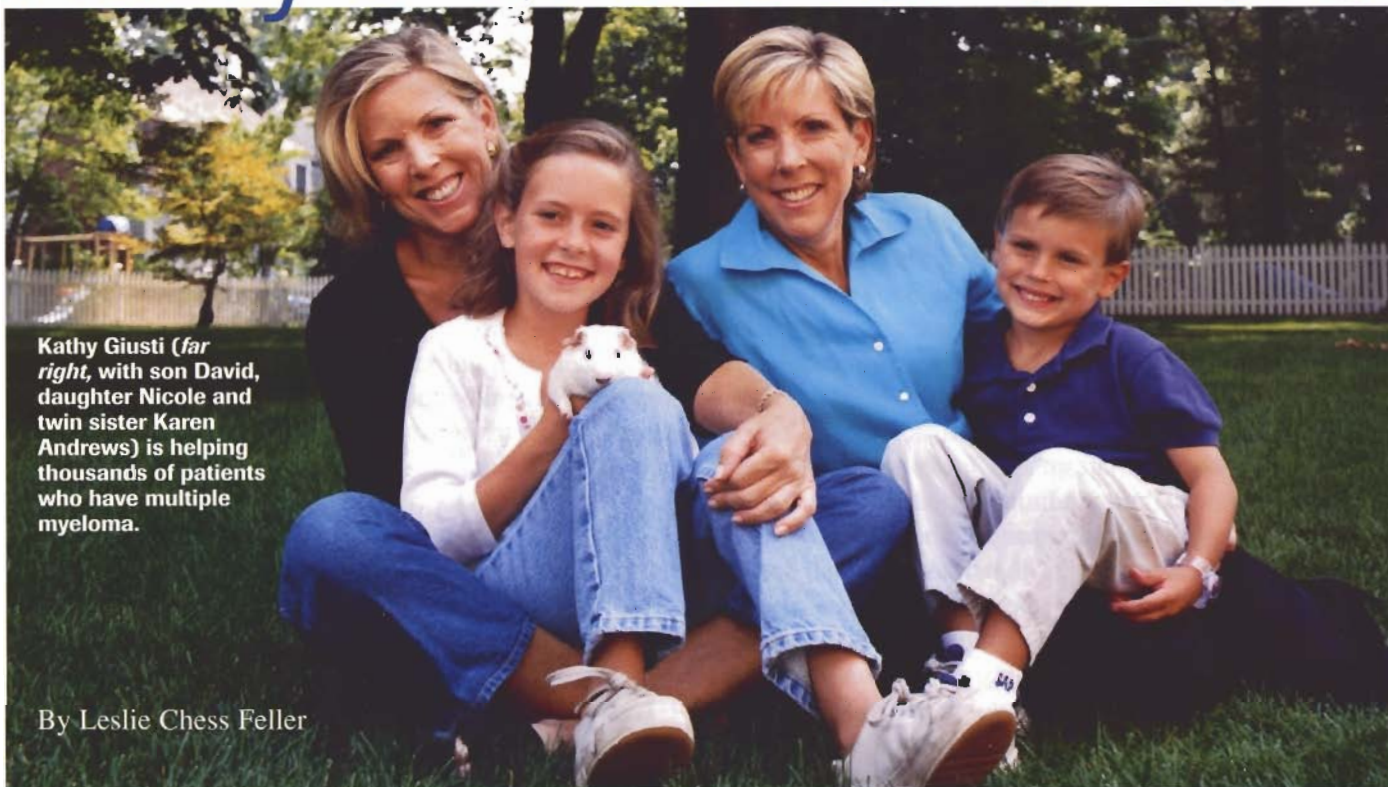


FamilyCircle

Women Who Make a Difference

Kathy's Quest for a Cure



Kathy Giusti (*far right*, with son David, daughter Nicole and twin sister Karen Andrews) is helping thousands of patients who have multiple myeloma.

By Leslie Chess Feller

Kathy Giusti, 44, stood in the Oval Office of the White House on May 14, 2002, as President George W. Bush signed the Hematological Cancer Research Investment and Education Bill into law. The legislation offers hope to 700,000 blood cancer patients nationwide. For Kathy the moment seemed unreal. Six years earlier

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she had been diagnosed with an incurable blood cancer called multiple myeloma. "I was told I might have only three months, at best three years, to live," she recalls.

During the ceremony Kathy had every right to feel exhilarated. In no small measure that law was the result of years of hard work by the Multiple Myeloma Research Foundation (MMRF), the nonprofit organization that she and her identical twin sister, Karen Andrews, co-founded not long after Kathy was diagnosed.

“What can I do in a short period of time to help the people I love?”

“I’ve always been the kind of person who looks ahead and plans for the future,” she says. “I still am, but my life has turned out to be very different from the one I imagined just seven years ago.”

On December 10, 1995, holding her then-18-month-old daughter, Nicole, in her arms, Kathy placed the last Christmas ornament on the tree in the living room of her home in Chicago and smiled at her husband, Paul. It seemed to Kathy that life couldn’t be much better.

But when she had a blood test during a visit to the doctor just a few days later, the results were devastating: Kathy had multiple myeloma, a cancer of the plasma cells and the second most prevalent blood cancer after non-Hodgkin’s lymphoma. “I put the Christmas tree up as a successful businesswoman with a wonderful family. When I took the tree down in the middle of January, I packed the ornaments away wondering if I’d ever open them again,” she says.

The illness explained her weight loss, fatigue and susceptibility to infection. Plasma cells produce antibodies that help the body fight infection, but when cell production runs rampant, it can cause excessive bone destruction, kidney failure, a weakened immune system and anemia.

At the time, Kathy was a senior pharmaceutical executive at the former G.D. Searle & Co., but she knew nothing about this deadly disease, which afflicts about 50,000 people in the United States. “I’m lucky my doctor was alert to the abnormal protein in my blood, because I don’t fit into the typical at-risk group,” she says. Multiple myeloma is twice as common in men as in women and is usually found in people over age 65 and among African-Americans. About 14,000 cases are diagnosed each year.

In those dark days her sister, Karen, an attorney living in Connecticut with her husband, John, and their children, came to her side. “She was the strong one,” Kathy says. “She helped me until I could help myself.”

Kathy’s cancer was discovered very early and was in a relatively inactive stage: The malignant cells had not yet caused bone destruction. Says Kathy: “My immune system was still able to hold the disease in check.”

Despite the grim outlook, Kathy wanted a second child. “I needed to live my life as if I were going to live,” she says. “I decided that if that was the last thing I did, it would be worth it.” David Giusti, born on May 5, 1997, was life triumphant in the face of terminal illness. “I was ecstatic,” she says. “It was one dream myeloma could not destroy.”

a month later the Giustis moved to Connecticut to be near family. “I knew my wife had to be near Karen,” says Paul. The twins had always been extraordinarily close. As children growing up in Blue Bell, Pennsylvania, they seemed inseparable. As young adults they attended the University of Vermont, Burlington, where they were roommates; after they married the two families took vacations together.

Friends and co-workers, meanwhile, were offering emotional support—and more. “People wanted to know how they could help find a cure,” says Kathy. Within months Karen, an associate general counsel at Time Inc., had helped Kathy establish a research fund.

“Things just took off,” says Kathy, after their first fundraiser on October 21, 1997, which raised more than \$450,000 for research fellowships. Two noted doctors, Kenneth Anderson, M.D., director of the Jerome Lipper Multiple Myeloma Center at Boston’s Dana-Farber Cancer Institute, and Philip Greipp, M.D., director of the hematological malignancies program at the Mayo Clinic, joined the fund’s scientific advisory board.

A few months later, they established the MMRF—now the world’s largest private funder of multiple myeloma research. To date it has distributed \$12 million in grants to researchers at 40 major institutions around the world.

Last May, at the 38th annual meeting of the American Society for Clinical Oncology, researchers presented several potential new treatments, two of which were discovered through studies partially funded by the MMRF. The drug Velcade, currently in advanced clinical trials, attacks myeloma cells by blocking the breakdown of certain key proteins. Revimid, another drug being tested, inhibits growth factors in the bone marrow necessary for tumors to

Since her diagnosis, Kathy Giusti has had many milestones (clockwise from top): a MMRF fund-raiser; with President Bush in the Oval Office; her daughter’s fifth birthday party.



thrive. Such research, Dr. Anderson says, represents “a big leap forward” in finding a cure.

“I can’t tell you what an experience it was to sit in the audience, hear that these new compounds have the potential to save lives and know that we helped pay for the research that discovered them,” says Kathy.

The foundation also sponsors weekend symposiums several times a year for researchers around the globe to update each other on new approaches and discoveries. “There’s every reason to be optimistic,” says Dr. Anderson, who suggests that myeloma is on its way to becoming, at the very least, a treatable chronic disease.

Kathy points out that these new options are already making an impact on the lives of myeloma patients. “By contrast to when I was diagnosed, today there is hope,” she says. “I’m living with this terrible disease constantly, day after day, and so are 50,000 other Americans. New therapies are extending the lives of myeloma patients, and each new compound discovered opens another door.”

Kathy is fortunate to be among the small minority of myeloma patients diagnosed with early-stage disease. A remarkable seven years later her cancer remains inactive. She has done well just having monthly intravenous infusions of a medication that prevents bone loss and increases bone density.

No one knows when Kathy’s myeloma will become active, but when it does, a stem cell transplant from her twin could buy her time. “If that day comes, I’ll be there with her,” Karen says. “We’re in this thing together, which comforts both of us.”

It’s a family joke that the twins, while physical duplicates of each other, are complete opposites in terms of personality. “Karen’s actually a lot more fun than I am,” Kathy says. “She’s relaxed and easygoing, just like Paul. I’m terribly compulsive and too serious.”

“Much, much too serious!” her twin says. “Karen wants me to come out and play,” says Kathy. “I wish I could, but I can’t. There’s too much I have to do.”

Meanwhile, Karen has tested negative for multiple myeloma but is participating in research being conducted by Dr. Anderson. “It’s very uncommon to find identical twins where one has cancer and the other does not,” he says. At the Dana-Farber Cancer Institute, Dr. Anderson is using the latest gene array technology to compare the sisters’ plasma cells. “Their genes are identical,” he says, “but sort of like a circuit box, certain ones are turned on, and others off, in each twin.”

Dr. Anderson is excited by the potential of what he has discovered. “We have already identified previously unrecognized genes, genes that are turned on in Kathy but not in Karen,” he says. “Those are intriguing discrepancies which we are currently investigating.” He adds, “There are environmental triggers as well, which we are working to identify.”



Geraldine Ferraro (right) and Kathy Giusti went before Congress in 2001 to get support for blood cancer research.

To her surprise and joy, Kathy has outlived the three-year plan she made when diagnosed. After crossing off every item on her original list, she sat down and wrote a new one. “I never really thought I’d get more time,” she says.

It has enabled her to expand the foundation and its mission. “At any given moment there are easily 200 people helping us as volunteers,” says Kathy. They join nine full-time staff members in planning fund-raisers, lobbying and getting medical information to the 20,000 visitors who log on to the foundation’s Web site monthly (www.multiplemyeloma.org).

As a member of the National Cancer Institute’s Director’s Consumer Liaison Group and the National Cancer Policy Board, she is also looking beyond myeloma. “I understand the patient community and the research community,” she says. “I understand industry. There are molecules out there that could save lives and they aren’t being developed. I’d like to bring the right people together to change that.”

When former New York congresswoman and vice-presidential nominee Geraldine Ferraro revealed in June 2001 that she has multiple myeloma, “awareness increased exponentially,” Kathy says. Ferraro was later invited as a special guest to the foundation’s annual fundraiser, where she told supporters, “My family and I believe Kathy Giusti has been a lifesaver in creating and leading what we consider to be the best vehicle for pushing research into the cure and treatment of this disease.”

That same year, with the help of Ferraro and U.S. Senator Kay Bailey Hutchison (R-Texas), whose brother has multiple myeloma, the MMRF, the Leukemia & Lymphoma Society and the Lymphoma Research Foundation launched a large advocacy effort in Congress. “That was a great start,” Kathy says, “but it wasn’t enough.”

A year later these same organizations returned to Washington with 300 volunteers from 34 states who were urging Congress to act on the Hematological Cancer Research Investment and Education Bill. Once it was approved and signed by President Bush, its supporters could finally celebrate. The law directs the federal government to authorize new blood cancer research and spearhead a number of educational programs.

But these accomplishments come at great personal cost. "I live with fatigue," says Kathy. "I live with infections that my immune system can't easily fight off so I have to take antibiotics prophylactically."

A hectic schedule that includes weekly travel means missing precious time at home. "Nicole, David and Paul need me," she says, "and I need them." But so many lives, including her own, are at stake.

"There are times," she admits, "when it all feels quite overwhelming. I'm a woman who's dying of cancer and I'm never able to step away from it. You can't imagine how difficult that is—to live it, breathe it, every single minute of every single day."

When not traveling, Kathy's in front of the computer in her home office in New Canaan, Connecticut, by 6 A.M., but work stops as soon as David, six, and Nicole, nine, are up. "I like to be there when they get up. We have breakfast together and walk to the bus stop," she says. "With the office two minutes away, I can be home when they get back. We'll play checkers, read together or do art projects." Nicole, she says, likes to bake; David is into books, tennis and soccer. "Paul is wonderful," she says. "I couldn't do what I do without his support."

Nicole and David don't know about their mother's illness yet. "The professionals we've consulted have advised us that children will ask when they are ready to be told," Kathy says. "They're still so young and this is such a hard thing for a child to have to live with." For now, David and Nicole have

simply been told that their mother "raises money so scientists can find medicines that help sick people feel better."

Says Kathy: "Nicole was six when she asked what I did when I had to go to work. She listened quietly, then went upstairs, emptied her piggy bank and came down with two dollars and seventy-two cents. 'Give this money to the scientists, Mommy,' she said." When the time comes that they have to tell their children that Kathy is sick, the Giustis hope they'll also be able to say, "Mommy's going to get well."

Meanwhile, Kathy is doing everything she can to make sure her family will be O.K. She keeps a daily journal and makes a point when writing not to dwell on despair, but to fill the pages with expressions of love, faith and optimism. "Someday Nicole, David, Paul and Karen will read this. I've written it for them," she says. "When you have cancer, that's all you think about: *What can I do in a short period of time to help the people I love?*"

Kathy says quietly: "This disease is unpredictable. People die from it. I've lost a lot of friends. So I don't take anything for granted anymore. I cherish every birthday, every holiday, every milestone.

"So many things I wished for came true, and right now that gives me strength," says Kathy. But if her family should have to go on without her, she takes comfort in knowing how much Nicole and David love their aunt. "Later on Karen will still be there, the closest thing to Mommy they could have," Kathy says. "When they look at my sister, I hope our resemblance will be like a piece of me they can hold on to." **FC**

